Universidade de Aveiro
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Escola Superior de Saúde da Universidade de Aveiro

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Dissertação apresentada à Universidade de Aveiro para cumprimento dos requisitos necessários à obtenção do grau de Mestre em Fisioterapia, realizada sob a orientação científica da Doutora Alda Marques, Professora Adjunta da Escola Superior de Saúde da Universidade de Aveiro.

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Palavras-chave *Core outcome set*; estudo qualitativo; entrevistas; reabilitação respiratória; DPOC

Resumo

Enquadramento: A doença pulmonar obstrutiva crónica (DPOC) é atualmente a quarta principal causa de morbilidade e mortalidade no mundo. A reabilitação respiratória (RR) é uma intervenção fundamental para a gestão da DPOC mas de acesso escasso. Apesar do "potencial" de melhoria do doente ser comumente utilizado como critério de acesso à RR, esta melhoria é altamente dependente das medidas que são utilizadas na RR. Atualmente, não existe um consenso relativamente ao conjunto mínimo de domínios (*Core Outcome Set* – COS) que devem ser avaliados nos programas de RR de pessoas com DPOC. Um COS tem o potencial de melhorar a consistência na literatura e diminuir o risco de viés nos resultados reportados, ao incluir domínios considerados relevantes para os diferentes intervenientes na RR.

Objetivo: Explorar os domínios da RR valorizados por doentes, cuidadores informais (CI) e profissionais de saúde (PS).

Métodos: Realizaram-se entrevistas semiestruturadas a 12 doentes com DPOC (83.3%♂, 70.8±5.2 anos, 50.7±17.5 VEMSpp, 27.2±3.9 IMC), 11 CI (18.2%♂, 68.4±7.9 anos, 5.3±7.0 anos a cuidar) e 10 os (20%♂, 40.7±14.3 anos, 6.7±9.7 anos de experiência). Os dados foram analisados através da análise qualitativa ao conteúdo e posteriormente através da análise temática, através do *software* NVivo.

Resultados: Este estudo gerou 44 domínios a serem avaliados na RR. Cinco temas, relevantes para todas as partes interessadas, foram gerados pela análise: ter uma mente sã num corpo são, eu (não) consigo, sentir-se realizado, saber mais para fazer melhor e evitar médicos e despesas. Apesar das perspetivas terem sido maioritariamente consensuais entre os participantes, alguns domínios (i.e., função pulmonar) foram valorizados apenas pelos PS. Para os doentes e CI, a RR foi principalmente valorizada pelo seu impacto na vida diária e papel na comunidade. Apesar de alguns participantes não reconhecerem benefícios da RR em domínios-chave da literatura, como a tolerância ao esforço, todos os participantes reconheceram pelo menos um benefício da RR.

Conclusão: Este estudo identificou um conjunto de domínios considerados relevantes para a RR de pessoas com DPOC, pelos diferentes intervenientes desta intervenção, que não são consensuais. Estes resultados poderão contribuir para o desenvolvimento futuro de um COS para programas de RR em pessoas com DPOC.

Keywords Core outcome set; qualitative study; interviews; pulmonary rehabilitation; COPD

Abstract

Background: Chronic obstructive pulmonary disease (COPD) is currently the fourth major cause of morbidity and mortality worldwide. Pulmonary rehabilitation (PR) is currently recommended as a fundamental intervention for the management of stable COPD. However, its access is very restricted. Although, the potential of improvement has been used as a criterion to determine patients' access to PR, the response is highly dependent on the outcomes measures used. Moreover, there is still no consensus on the minimum outcomes that should be assessed (*Core Outcome Set* – COS) in PR. A COS has the potential to improve consistency among trials and lessen the risk of outcome reporting bias, by including outcomes relevant to different stakeholders.
Aim: To explore outcomes of PR valued by patients, informal carers (IC) and health professionals (HP).
Methods: Semi-structured interviews were conducted with 12 patients (83.3%♂, 70.8±5.2 years, 50.7±17.5 FEV_1pp, 27.2±3.9 BMI), 11 IC (18.2%♂, 68.4±7.9 years, 5.3±7.0 years of caregiving) and 10 HP (20%♂, 40.7±14.3 years, 6.7±9.7 years of experience). Data were analysed following a content analysis approach and thematic analysis afterwards with NVivo software.
Results: This study generated 44 outcomes to be assessed in PR. Five relevant themes to all stakeholders were generated from the analysis: having a healthy mind in a healthy body; I can('t) do it; feeling fulfilled; knowing more, doing better and avoiding doctors and expenses. Although perspectives were mostly consensual among stakeholders, some outcomes (i.e., pulmonary function) were only valued by HP, whereas patients and IC valued PR for its impact on their day-to-day lives and role in the community.
Although some participants did not recognize PR effects in key outcomes reported in the literature such as exercise tolerance, all participants reported at least one positive outcome.
Conclusions: This study identified a set of outcomes relevant for the different stakeholders involved in PR, that are not consensual. These results could contribute to the development of a future COS for PR in patients with COPD.

Abbreviations and/or acronyms

BMI – Body mass index

CAT - COPD assessment test

CI – Confidence interval

COMET - Core Outcome Measures in Effectiveness Trials

COPD – Chronic Obstructive Pulmonary Disease

COS – Core Outcome Set

FEV_1pp - Forced expiratory volume in one second, percentage predicted

FVCpp - Forced vital capacity, percentage predicted

GOLD - Global initiative for chronic obstructive lung disease

HADS – The hospital anxiety and depression scale

HP – Health professionals

HRQoL – Health related quality of life

IC – Informal carers

ICC – Intraclass correlation coefficient

ICF - International classification of functioning, disability and health

MCID - Minimal clinically important difference

mMRC - Modified British medical research council questionnaire

PA – Physical activity

PR – Pulmonary rehabilitation

SGRQ - St. George respiratory questionnaire

VEMSpp – Volume expiratório máximo num segundo, percentagem prevista

ZBI – Zarit burden interview

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1. Theoretical Framework

Chronic obstructive pulmonary disease (COPD) is currently the fourth major cause of mortality and is expected to be the seventh cause of disability-adjusted life years by 2030 (1, 2). COPD is now considered a public health issue and has gained awareness for its substantial health, social and economic burden worldwide (3, 4). Furthermore, it is estimated to affect 11.7% of the population worldwide and 9.3% of the Portuguese population (5, 6).

COPD has a negative impact on both physical and mental domains of a person's health status (7) having not only pulmonary but also extrapulmonary manifestations such as muscle mass depletion, an abnormal body composition, exercise intolerance, reduced mood status and reduced self-reported daily physical activity (8). Moreover, it has a negative social impact on emotional, relational and financial/employment life dimensions (9, 10).

Pulmonary rehabilitation (PR) is established as a fundamental intervention for the management of stable COPD as it has shown to improve symptoms, exercise tolerance, muscle strength, psychological well-being and health-related quality of life (HRQoL) of these patients (11-14). Although being a highly effective intervention and more cost-effective than any pharmacological treatment, there are still patients that allegedly do not respond to the intervention (15-19). Response to treatment has been used as a criterion to determine patients' access to PR (20), however the type of response is differential among various outcomes and outcome measures (21, 22). Thus, in order to ascertain if there are indeed non-responders to PR, the choice of outcomes and outcome measures should be pondered, and assessing the response in multiple outcomes rather than key performance outcomes, such as exercise tolerance, seems to characterise best the response to PR in patients with COPD (16). Additionally, as patients with COPD are a heterogeneous population with several comorbidities, divergent methods and outcomes are used to evaluate the effects of PR, even when similar programs are being compared, which results in miscellaneous outcomes reported in the literature (23-25).

The lack of homogeneity in the selection of outcomes and outcome measures is of most importance, as it can hamper the conduction of meta-analysis and hinders an accurate interpretation of the effects of PR in several settings (26-30). Therefore, in order to overcome these barriers, a consensus in reporting outcomes of PR in patients with COPD has been advocated (31-33). Similarly to other clinical fields, the heterogeneity in clinical trials of PR in patients with COPD, due to the wide variety of outcomes and outcome measures, can be minimised with the development of a Core Outcome Set (COS), by defining a minimum set of outcomes that should be consistently measured and reported (34-38). Hence, defining a COS for PR in patients with stable COPD has the potential to improve the quality of the assessment of PR outcomes by generating consistency among trials, lessening the risk of outcome reporting bias, and including outcomes relevant to different stakeholders, including not only researchers but also patients and carers (35). Other COS have successfully accomplished these goals, by achieving a consensus following the guidelines of The Core Outcome Measures in Effectiveness Trials (COMET) initiative (39). COMET proposes the inclusion of different stakeholders in the process of developing a COS,

which should be accomplished in four stages: identifying existing knowledge (e.g., a systematic review of the literature), qualitative research with stakeholders whose views are poorly described in the literature and yet important (previous COS have conducted focus groups or the included stakeholders only on the Delphi study), assess the level of importance of outcomes and achieve consensus through key stakeholders (i.e., Delphi study) and report the work (i.e., final publication of the COS with recommendations) (36, 39-41).

Thus, this study aimed to contribute for the development of a COS for PR in patients with stable COPD, by developing one of the stages of a COS – a qualitative study with interviews to different stakeholders - patients, informal carers (IC) and health professionals (HP).

2. Methods

This dissertation comprehends one of the most relevant methodological phases, recently recommended by the COMET initiative (i.e., a qualitative study) (39). Although previous COS have mainly recurred to focus groups, interviews are now being encouraged by the COMET initiative, as they can potentially bring new insights (39). Thus, a qualitative study with in-depth interviews was conducted to identify outcomes of PR reported as relevant by different stakeholders (i.e., patients, IC and HP). This COS is registered in the COMET initiative database (http://www.comet-initiative.org/studies/details/1151).

2.1. Ethics

This study was approved by the Ethics Committee of the Research Unit of Health Sciences at the School of Nursing in Coimbra (UICISA), Portugal (P466-10/2017) (Annex I).

Prior to the interviews, a written information sheet was given to all participants explaining the objectives and details of the study and any doubts were clarified (Appendix I). All participants received and signed an informed consent before enrolling the study (Appendix II) that will be kept locked in a cabinet in the School of Health Sciences, University of Aveiro, Portugal, for 10 years (following the university regulations). Only the researchers from the study will have access to these data.

2.2. Design and Participants

A qualitative phenomenological and interpretive study was conducted in the centre and north regions of Portugal. Stakeholders were divided into three groups: patients, IC and HP. Patients and IC were recruited from a community-based PR program in Aveiro, whereas HP were recruited from the Lab3R – Respiratory Research and Rehabilitation laboratory's network, known to implement PR programs. These professionals were contacted by e-mail or phone call.

The group of patients integrated patients with stable COPD (n=12). Patients were eligible if they were diagnosed with COPD and undertook a PR program in a stable

phase of their disease (i.e., no acute exacerbations in the last month) (42). IC (n=11) were significant people indicated by patients and were included if they were adults (≥18 years old) and supported the patients in their daily living activities, health care, and/or offered emotional support (43). Participants from these two groups were excluded if they had signs of substance abuse (e.g., alcohol or drugs) or were diagnosed with major psychiatric disorders, such as severe depression, or cognitive impairments.

HP (n=10) were included if they were at some moment involved in the design, support, assessment and/or implementation of a PR program that included patients with stable COPD.

A sample size calculation was not possible to perform due to the nature of the methodological approach. However, following qualitative research principles, the sample was complete when data saturation was achieved, that is, when interviews did not generate relevant, additional information (44). Efforts were made to ensure a maximum variation strategy, i.e., to include patients with different grades of the disease (different airflow limitation), assessed through spirometry (45), COPD assessment test (CAT) and number of exacerbations (4).

2.3. Measures

2.3.1 Quantitative Measures

All participants followed a specific protocol, described below, according to the group they integrated. A structured questionnaire based on the international classification of functioning, disability and health (ICF) checklist was used to characterise the sample (46). Sociodemographic (age, gender, level of education, marital status and usual occupation) data were collected from all participants. Additionally, IC were asked to state their relationship with the patient and years of providing care. HP were questioned about the type of involvement in PR programs (design, implementation, support) and duration of their experience (quantified in years).

2.3.1.1 Patients

For the group of patients, anthropometric and clinical data were also collected, to enable clinical differentiation between patients. Anthropometric data consisted of measuring height, weight and body mass index (BMI). Clinical data included pulmonary function parameters – percentage predicted of forced expiratory volume in one second (FEV_1pp), percentage predicted of forced vital capacity (FVCpp) and Tiffenau index (FEV_1 ratio - FEV_1/FVC); smoking status/history; comorbidities; number of exacerbations; medication; level of dyspnoea during activities; physical activity (PA) habits; disease impact; anxiety and depression and HRQoL.

Anthropometric data

Height and weight were measured through a scale. BMI was determined using a bioelectrical impedance instrument (47) and interpreted as normal within the range

18.5-25 kg/m^2 (48). These data are related with the level of dyspnoea (r=0.48) and FEV_1 (r=0.48) and are not responsive to PR (49-52).

The assessment of body composition in patients with COPD is important, as it is known that this disease results in a loss of muscle fat free mass, which has consequences in exercise capacity and functionality (49). Moreover, BMI is a strong predictor of mortality among patients with COPD, with a low BMI associated with increased mortality (HR= 1.3, 95%CI 1.0–1.6; HR=3.2, 95%CI 1.5-7.0) (53).

Pulmonary function

Pulmonary function was tested using spirometry, considered to be the gold standard to diagnose persistent airflow limitation (4, 45). The international recommendations were followed (4, 45). Patients were asked to maintain throughout all the procedure a correct posture while sitting. A nose clip was then attached and patients were asked to exhale completely and afterwards to place the mouthpiece in their mouth and close the lips around it, inhaling maximally and then exhaling maximally until no more air could be expelled. The coaching was delivered vigorously, and repeated for at least 3 manoeuvres as recommended (45). A minimal clinically important difference (MCID) of 5 to 10% from baseline in FEV_1pp has been suggested as a relevant indicator for monitoring pulmonary function (54).

Smoking history

The history of smoking was assessed by asking patients their current or previous smoking history, number of cigarettes per day and number of years they smoked. Smoking pack-years was determined by the formula - number of pack-years = (packs smoked per day) x (years as a smoker).

Comorbidities and medication

Comorbidities were assessed by asking patients their other health problems and/checking the clinical notes, whenever possible, and the names of the correspondent medicines were registered.

Number of exacerbations

Patients were asked about the number of respiratory crisis, defined as a worsening of respiratory symptoms that leads to additional therapy (4).

Dyspnoea

Dyspnoea is one of the most incapacitating symptoms for patients, limiting their participation in daily living activities (55, 56). Therefore, it was assessed with the modified British medical research council questionnaire (mMRC). This scale is commonly used to assess breathlessness during daily activities in patients with COPD and comprises 5 grades of dyspnoea, where 0 represents no dyspnoea and 4 almost complete incapacity due to dyspnoea (4, 57). Higher scores indicate worse breathlessness during activities.

This scale is commonly used in COPD (4), has shown good test-retest reliability with the 95% confidence interval (CI) (ICC=0.82), and moderate positive correlations with

disease severity based on FEV_1pp (r=-0.67), and HRQoL based on the St. George respiratory questionnaire (SGRQ) (r=0.65) in patients with stable COPD (58-60). It is also usually used as a discriminant between COPD grades and it has an established MCID of 1 point (21).

Physical activity

PA levels are known to be diminished in people with COPD (14, 61, 62). Therefore PA was assessed with the brief physical activity assessment tool, which comprises two questions about the frequency of practice of vigorous or moderate physical activity in one week (63). The question assessing vigorous PA has 3 items, whereas the moderate intensity question has 4 items. The sum of both questions determines the patients' PA levels, with a patient being sufficiently active with a score equal or above 4 points (63). This instrument has the advantage of being simple to apply and interpret, and has been shown to be a reliable (inter-rater reliability with 95%CI kappa=0.53) and a valid tool (criterion validity with 95%CI kappa=0.40) to assess moderate and vigorous PA (63).

Impact of COPD

The impact of this disease on patients' lives and their family has also been recognised in the literature (7, 10, 64, 65). Thus, to further comprehend the disease impact on patients' lives, CAT was used, as it measures patients' well-being in their quotidian (66). CAT is a 6 point Likert scale, where higher total scores are indicative of greater impacts (67). It is a well-studied measure, with a scoring system ranging from 1 to 5 and total scores from 0 to 40. CAT has strong clinimetric properties such as internal consistency (α=0.88), and test-retest reliability (95% CI ICC=0.8) (68), highly correlated with FEV_1 and SGRQ (r=0.84)(69), and is a responsive measure to PR (effect size d=0.4) (66, 67). Its MCID is of -2.9 points (70). It has been suggested that a cut-off of 10 points discriminates patients, with 10 or more points indicating a significant impact of the disease (71).

Anxiety and depression

The symptoms of anxiety and depression have been found to be commonly present in patients with COPD (72-74). An understanding of these parameters in the population being studied is fundamental as they are strongly related to the disease progression and are predictors of poor HRQoL (75, 76). Therefore, anxiety and depression symptoms were assessed through the hospital anxiety and depression scale (HADS), a 14-item scale that allows separating the anxiety score from the depression score. A score equal or superior to 8 points in each subscale, indicates the presence of anxiety or depression (77), permitting a more detailed characterisation of the mental status of each patient with COPD (78). It has good internal consistency (α=0.91)(79) and an MCID of 1.6 points for PR (80, 81).

HRQoL

HRQoL is usually compromised in patients with COPD however, the extent of this compromise varies throughout the course of the disease (82-84) and differs from the population being studied, as it is known to be related with exercise tolerance, dyspnoea, anxiety, wheezing, body composition, fatigue and coping strategies (85). Thus, it is important to understand the baseline level of the population being studied to

tailor interventions, such as PR (13, 86). Therefore, HRQoL was assessed with the SGRQ, a disease-specific and widely used questionnaire in patients with COPD (87, 88). The SGRQ has excellent internal consistency (α=0.93) (89), good reliability (ICC=0.81-0.86), high validity (correlated with CAT r=0.73) (90) and is a responsive tool (effect size=0.87) to PR (91).

2.3.1.2. Informal Carers

Burden of COPD

The burden of COPD is also significant, not only on patients, but also on IC (10, 64, 65), however, a comprehensive understanding of this parameter and its implications for the daily life of families is yet limited. Therefore, IC's burden was assessed through the Zarit burden interview (ZBI). ZBI has a range score from 0 to 4, in which 0 represents "never" and 4 represents "nearly always" (92, 93). Scores 41–60 indicate moderate to severe burden, and scores ≤40 indicate mild to no burden (94). Although it has not been yet validated for COPD, ZBI has shown to be an adequate tool for assessing the burden in people with dementia, cancer and stroke (93, 95-97). This study will contribute to the validation of the ZBI in people with COPD, a measure already used in various studies in this population (94, 98-100).

2.3.1.3. Healthcare professionals

Nature of professions

The nature of professions often determines how professionals perceive the world (101, 102). Therefore, this data was collected by asking the profession to the interviewed HP. Although many professions could be involved, it was expected to cover physiotherapists, nurses, medical doctors and psychologists, as these HP are commonly involved in PR (103).

Role in PR programs

PR involves a multidisciplinary team for the management of COPD (12, 104). The role of HP was asked and categorised into either design, support or implementation. HP could be involved in the planning of the PR program, support through assessment or psychoeducation, or implementation in either the exercise or educational component (12, 105).

Experience in PR programs

HP have been described by patients as a key for the success of PR (106). Since the perception of outcomes that are important could be influenced by the degree of involvement in PR programs, HP's experience was questioned (i.e., amount of time in years involved in such programs).

2.3.2. Interviews

Interviews were recorded with two recording devices, to assure full collection of audio data. The interviews were conducted in a semi-structured format, following a guide with open ended questions within the scope of the research, for each group of participants (Appendix III). This method has been described as a powerful approach to guide interviews, allowing participants to follow a line of reasoning, although maintaining the ability to express their feelings, which would not be possible using a rigid format (107-109).
Questions for patients were related to their participation in PR programs. Specific aspects approached in the interviews involved the settings of those programs (i.e., community-based, hospital-based, home-based), family members, friends or people that were involved in conducting the programs, their experience of participating in PR, motivational factors to enrol the program and maintain their adherence, reasons for quitting (if applicable), positive and negative effects they experienced during PR (including outcomes most valued), and suggestions to modify their experience during PR.

IC were also asked about their experience providing support during PR, motivational factors on providing support, reasons for quitting or stopped being involved (if applicable), positive and negative effects of PR (and most valued outcomes) on patients and themselves, and suggestions to modify IC's experience during PR.

Questions for HP were focused on their experience of being involved in a PR program, the settings they worked in, people involved in those programs, the aims of their PR program, positive and negative effects of PR, main outcomes perceived by them for patients with COPD participating in PR and suggestions for PR programs.

2.4. Procedures

Participants were contacted to enrol the study and the choice of setting was given to patients and IC, to assure a comfortable environment to perform the interviews (110, 111). Healthcare professionals were either interviewed at their workplace or by real time video, using the skype platform, thus avoiding financial and geographical constraints (112, 113).

All participants firstly completed the structured questionnaire (in a written format or orally) to characterise the sample. Sociodemographic, anthropometric and clinical data (in case of patients) were first collected. Then, patients and IC were given the questionnaires to fill in. Patients then performed spirometry as previously described.

After these data collection, participants were asked again for their permission to record the interviews. The interviews were paced at a slow rhythm, allowing participants to develop their rationale, to give more in-depth details and to establish a solid rapport (114). Before and after the interviews, space for casual conversations was given to reassure a friendly inviting environment (114). After interviewing the participants, the audio data was transferred from the recorder, stored in a computer with only researchers' access permissions and afterwards deleted from the original device.

Participants' names and others emerged from the interviews were then coded to protect their identity and to preserve confidentiality.

2.5. Data Analysis

2.5.1. Quantitative Analysis

Quantitative data from each group were analysed separately, using SPSS statistics software version 23 (IBM, SPSS Inc., Chicago, Illinois). Descriptive statistics were applied, in order to characterise participants according to sociodemographic, anthropometric and clinical variables as appropriated.

2.5.2. Qualitative Analysis

Interview analysis was divided in two stages, the first to define a list of outcomes and the second to gain in-depth understanding of the views of different stakeholders on pulmonary rehabilitation. The analytical process began during data collection, which allowed researchers to enhance the questions and achieve more in depth details on subsequent interviews (115).

Stage one: the interviews were transcribed, checked for accuracy and then coded using inductive latent content analysis, where outcomes from the participants' own words were gathered by content (e.g. "…I can shower by myself, and I can also put my shoes on" "…I do not have to enter the shower to help him." – improving functional performance) (116). The percentage of participants of each stakeholder group who mentioned each outcome was recorded.

Stage two: the outcomes were collapsed and interpreted as themes with to gain deeper understanding of the perspectives of the different stakeholders on PR (117). NVivo software was used to aid data organisation and visualisation (version 11, QSR International Pty Ltd, 2017, Victoria, Australia) (118).

2.6. Trustworthiness

Reliability of qualitative data has been described as the trustworthiness of interpretations (119). To ensure the credibility of interpretation, the memos and decisions were recorded. Outcomes collapsed into each of the themes were defined by reaching consensus through discussions between two independent researchers (120). A Cohen kappa was computed for agreement between the two researchers (121).

3. Results

3.1 Participants characteristics

A total of 33 participants were interviewed (12 patients with stable COPD, 11 IC and 10 HP). The mean interview duration was 45 minutes. Patients were mostly males with BMI 27.2±3.9 (kg/m^2). 59% (n=7) were grade II, 33.3% (n=4) were grade III, and 8%

(n=1) were grade IV, according to airflow limitation severity (FEV_1pp 50.7±17.5, FVCpp 83.2±20.5, FEV_1/FVC 48.3±15.5). Patients were also mostly of grade A of GOLD (n=6, 50%), followed by grade B (n=3, 25%), D (n=2, 17%) and C (n=1, 8%). 1 of the patient was a current smoker and the mean smoking of all patients was 57.4±53.0 pack-years. Most patients had at least 1 comorbidity (2.5±1.8). IC were mostly females, 100% spouses, with an average of 5 years of caregiving (5.3±7.0 years) and mild burden of care (16.2±19.9 total ZBI score). HP were mostly females and researchers who designed and implemented the program (n=5, 50%), only implemented the program (n=4, 40%) or provided support (n=1, 10%), with 6.7±9.7 years of experience in PR programs.

Table 1 describes the sample characteristics per stakeholder group.

Table 1 - Participants characteristics (n=33).

	Patients (n=12)	IC (n=11)	HP (n=10)
Age, years	70.8±5.2	68.4±7.9	40.7±14.3
Sex, n (%)			
Male	10 (83.3%)	2 (18.2%)	2 (20%)
Female	2 (16.7%)	9 (81.8%)	8 (80%)
Academic qualifications, n (%)			
Basic education	8 (75%)	7 (63.6%)	0 (0%)
Intermediate education	1 (8%)	4 (36.3%)	0 (0%)
High education	2 (17%)	0 (0%)	10 (100%)
Marital status, n (%)			
Single	0 (0%)	0 (0%)	6 (60%)
Married	12 (100%)	11 (100%)	3 (30%)
Divorced	0 (0%)	0 (0%)	1 (10%)
Occupation, n (%)			
Restaurant owner	1 (8.3%)	0 (0%)	0 (0%)
Housekeeper	0 (0%)	4 (36.4%)	0 (0%)
Physiotherapist	0 (0%)	0 (0%)	2 (20%)
Medical doctors	0 (0%)	0 (0%)	2 (20%)
Nurses	0 (0%)	0 (0%)	2 (20%)
Researchers	0 (0%)	0 (0%)	4 (40%)
Retired	11 (91.7%)	7 (63.6%)	0 (0%)
Total CAT, score	13.8±6.1	----------	----------
Total SGRQ, score	37.4±14.7	----------	----------
HADS-A, score	4.9±2.6	----------	----------
HADS-D, score	5.5±3.1	----------	----------
Number of AECOPD on previous year	0.9±1.0	----------	----------
mMRC, grade	1.8±1.0	----------	----------
PA, n (%)			
Sufficiently active	6 (50%)	----------	----------
Insufficiently active	6 (50%)	----------	----------
Number of medication, n (%)	4.3±3.1	----------	----------
Bronchodilators	12 (100%)	----------	----------
Cardiovascular medication	6 (50%)	----------	----------
Antidiabetics	2 (17%)	----------	----------
Gastric acid modifier	2 (17%)	----------	----------
Gout suppressants	2 (17%)	----------	----------
Analgesics	1 (8.3%)	----------	----------
Anxiolytics	1 (8.3%)	----------	----------

Results are expressed in mean±standard deviation unless otherwise stated.

CAT – COPD assessment test; SGRQ – St. George respiratory questionnaire; HADS – The hospital anxiety and depression scale; AECOPD – acute exacerbation of COPD; mMRC – Modified British medical research council questionnaire; PA – Physical activity.

3.2. Stage one: list of outcomes

A total of 44 outcomes were identified from the interviews. The most reported outcomes across all stakeholders were “Improving functional performance” (67%) and “reducing and taking control over dyspnoea” (64%). Of the 44 outcomes, 38 were perceived as positive and 6 were considered negative outcomes of PR. A more detailed description can be found on Table 2.

Table 2 – Reported frequency of outcomes per stakeholder.

Theme/outcomes	Total, n (%)	Patients, n (%)	IC, n (%)	HP, n (%)	Transcriptions
Theme: having a healthy mind in a healthy body					
Positive outcomes					
Improving exercise tolerance	16 (48%)	6 (50%)	2 (18%)	8 (80%)	"…walking more and not feeling so tired. One of the things I liked the most was being able to walk for a longer period of time after being here (program)." – MJ (patient) "Before, when we went walking together he had to stop and do something. Now he comes with me and walks without stopping. I think that now I get tired faster than him." – IA (IC) "Patients had this habit of counting the number of times they stopped in the access ramp. As the program progressed they told us they had to stop fewer times until they did it without stopping." – FM (HP)
Increasing muscular strength	6 (18%)	2 (17%)	0 (0%)	4 (40%)	"I could not do more than five repetitions. Now I can do ten repetitions, twice, with relative easiness." (patient) "We assess muscular strength before and after the program, and I think it increases after PR" – PR (HP)
Achieving a healthy weight	5 (15%)	0 (0%)	1 (9%)	4 (40%)	"Before the program he was very skinny, it hurt just of looking at him." – MA (IC) "We saw the progress, the change in body composition, the loss of fat mass and the gain in muscle mass, and in cachectic patients the gain in muscle mass without significant changes in fat mass" – FM (HP)
Increasing or maintaining levels of physical activity	12 (36%)	5 (42%)	3 (27%)	4 (40%)	"Now I try to do the exercises at home. I do them almost every day." – MM (patient) "He was doing better, feeling good. He even used to walk to the fort and back." – DP (IC) "We have people that finish the program and go to the gym. Of course, we are not talking about the more severe patients, but in more mild patients that happens, and for me that is a benefit. People understand that they need to keep having an active life." – AO (HP)
Improving balance	6 (18%)	3 (25%)	0 (0%)	3 (30)	"I gained more confidence and balance. It changed everything for me." – MJ (patient) "… and on balance, we see that patients with COPD have balance deficits and we can tell its improvement" – CP (HP)

Improving functional performance	22 (67%)	8 (67%)	4 (36%)	10 (100%)	“Now I can take a shower by myself, and I can also put my shoes on.” - JC (patient) “When he goes showering I do not do what I did before, I do not have to enter the shower to help him. Now he takes a shower on his own.” – MC (IC) “We have people that stopped going shopping and now they go and they garden” – TP (HP)
Improving mobility and agility	6 (18%)	3 (25%)	0 (0%)	3 (30%)	“I felt good because I became looser, I was very stiff before.” – AS (patient) “They improve their agility to do some tasks, their body reactions become sharper.” – AO (HP)
Reducing pulmonary function decline	6 (18%)	0 (0%)	0 (0%)	2 (20%)	“It is not mandatory to assess pulmonary function before and after the program, but sometimes we do it for a more detailed assessment and there is a change in residual volumes on patients with hyperinflation.” – PS (HP)
Improving body awareness	1 (3%)	0 (0%)	0 (0%)	1 (10%)	“They gain more body awareness and acknowledge their limitations better.” – CP (HP)
Improving HRQoL	7 (21%)	0 (0%)	1 (9%)	6 (60%)	“What I value most in pulmonary rehabilitation is the quality of life it gives to patients. They become more integrated in their families and in the society.” – AC (HP)
Improving well-being	7 (21%)	3 (25%)	3 (27%)	0 (0%)	“The feeling of getting better, of feeling better, I feel more comfortable inside myself. The machine is more tuned.” – CM (patient) “I liked that he went to the program, he was feeling good, I never told him not to go. I thought it was doing him well.” – MV (IC)
Managing fatigue, improving stamina and exercise recovery	16 (48%)	5 (42%)	5 (45%)	5 (50%)	“I feel like I have more energy, for me and for others.” AB (patient) “I saw changes. More involvement, more drive, more stamina, more energy.” – MS (IC) “Is the capacity they gain in their usual activities, they do it more comfortably and with less fatigue. (…) That is what we feel it makes the difference: the relationship between the symptoms and the capacity to perform activities.” – PA (HP)
Reducing anxiety and fear	15 (45%)	6 (50%)	0 (0%)	9 (90%)	“Yes anxiety. I overcame a lot and the program had an impact.” – AB (patient) “They become less anxious about the future, with less fear of the unknown. They become more adapted to their condition and the stress levels decrease. I think they feel they are able to manage better.” – AO (HP)
Reducing depression	5 (15%)	0 (0%)	0 (0%)	5 (50%)	“In terms of psychological well-being, when they start the program they have trouble coping with depression or frustration because of the activities they are not capable of doing. But after the program the depression goes down as they feel more capable and with more confidence.” – CP (HP)

Reducing and taking control over dyspnoea	21 (64%)	10 (83%)	5 (45%)	6 (60%)	"I feel less breathlessness, I learned how to breathe, I used to do it inversely." – JS (patient) "I think he feels better. Now and then he still feels breathlessness, but not as before." – FS (IC) "In terms of symptoms, it is the first thing they gain and it is a significant improvement. Most of them, one of the first things they learn is how to control dyspnoea." – FM (HP)
Improving bronchial hygiene and cough	4 (12%)	2 (17%)	0 (0%)	2 (20%)	"I used to cough a lot during the night, and now I don't have so much cough. I really got better." – MM (patient) "Some patients have more sputum and after the program there is a decrease." – FM (HP)
Improving the quality of sleep	3 (9%)	1 (8%)	2 (18%)	0 (0%)	"I had another positive aspect! In bed, I started sleeping better." – JS (patient) "He was constantly waking everyone up in the house during the night. Then he started sleeping better and now I don't wake up at night either." – FT (IC)
<u>Negative outcomes</u>					
Increasing fatigue	1 (3%)	0 (0%)	1 (9%)	0 (0%)	"I feel that the next day he was more tired than usual" – MS (IC)
Increasing pain	8 (24%)	5 (42%)	0 (0%)	3 (30%)	"The only negative effect was the day after, the muscle pain, but it went away." – MS (patient) "With training, they have more articular pain, and sometimes it can lead to dropping out of the program." – PA (HP)
Theme: I can('t) do it					
<u>Positive outcomes</u>					
Improving mood	10 (30%)	3 (25%)	3 (27%)	4 (40%)	"I get in a good mood because we (patients) are always joking. The other day I couldn't stop laughing." – JC (patient) "With no doubt, I feel that he is more often in a good mood." – IA (IC) "The mood (…) I can't quantify it, but in a day-to-day basis I see that they laugh, they joke around, and they talk and tease each other and me all the time. They are more excited and accept the challenges better. They even start wanting to be challenged." – TP (HP)
Staying motivated and feeling confident	18 (55%)	8 (67%)	4 (36%)	6 (60%)	"… a will to do more, to go again, a good anxiety, not bad". – CM (patient) "…she started to feel more motivated, more opened, more available to face the challenges of her own life." – AB (IC) "I feel that pulmonary rehabilitation has a huge impact on motivation. I had one patient that at the beginning of the program was reluctant to do exercise and told

					me he couldn't. Now he tells me that he has a clothes peg scheme. He puts the clothes pegs in one table and carries them to another. There was an inversion of events. Now he gets really excited ant tells me how many pegs he transports." – PR (HP)
Managing expectations	7 (21%)	1 (8%)	1 (9%)	5 (50%)	"I went because I expected to get better, I became hopeful." – MS (patient) "I told him to go because I hoped he would get better". – FS (IC) "We see that they come with hope, they see the light at the end of the tunnel, they see that this works and we give them hope, even to families." – CP (HP)
Improving coping skills	5 (15%)	4 (33%)	0 (0%)	1 (10%)	"I started to realise that I could do things, some limitations were in my head."- JC (patient) "I think that they cope better because they see that they are not the only ones with the problem, and when they see a patient with oxygen and realise that that person travels, goes on a plane and does everything they like to do, the situation becomes less of a monster." – TP (HP)
Getting enjoyment and pleasure	9 (27%)	7 (58%)	1 (9%)	1 (10%)	"I liked the program very much. Due to the attention, exercises and dedication to do more and better." – MC (patient) "At beginning, she wasn't very excited. But then I saw that she had fun, she liked it and she got a lot better." – AM (IC) "We had a lot of fun. They joked a lot with me and each other. Sometimes I had to stop it so they would also work." – TP (HP)
Theme: feeling fulfilled					
<u>Positive outcomes</u>					
Being more sociable	13 (39%)	5 (42%)	2 (18%)	6 (60%)	"It was a good involvement, even with other couples. The social part of my life also changed." – AB (patient) "We created new friendships with people that have the same problem. It was good to see that we are not the only ones. That was very important." – AB (IC) "People that were very isolated come to the program and share rides, they start coming to our Christmas parties and see friends they made when they were in the program. Some things they don't tell us but we see." – AO (HP)
Improving predisposition for hobbies	6 (18%)	4 (33%)	2 (18%)	0 (0%)	"I felt that I gained a new occupation for my free time." – JS (patient) "While some people languish due to the disease, here it was not the case. Since she came here - she came out of her shell, she started volunteering, and wanting to do new things." – AB (IC)

Having meaningful support	18 (55%)	7 (58%)	3 (27%)	8 (80%)	"We see people that don't give up due to the amazing support you give. You are all caring, you motivate, you support, and I think that's important. You treat all of us with respect and affection." – JS (patient) "The family supported him and we told him to go because he felt better and it was important to him." – MR (IC) "The role of the family is very important. Some family members are barriers at the beginning, and we try to work with them so they can see that patients can do the program and should be motivated by them." – JS (HP)
Having a purpose, feeling of self-efficacy	18 (55%)	2 (17%)	2 (18%)	2 (20%)	"Now I am more careful. I try to take care of my health because I want to live more years to see my grandchildren grow." – JS (patient) "She started feeling more in control of the situations, more capable to achieve things." – AB (IC) "The frustration starts decreasing and they regain a sense of self-efficacy." – CP (HP)
Keeping an active sexual life	2 (6%)	0 (0%)	0 (0%)	2 (20%)[+]	"When I talked with a patient about the sexual positions he could do with less dyspnoea he was very interested and told his wife to get going while we talked. He was very interested." – PS (HP)
Feeling independent	5 (15%)	2 (17%)	0 (0%)	3 (30%)	"Even though she still helps me on some things, I can do more on my own, such as showering or putting my shoes on." – JC (patient) "Most patients value being more independent and happy." – PS (HP)
Reducing social embarrassment and frustration	8 (24%)	2 (17%)	0 (0%)	3 (30%)	"I used to be ashamed, because I wasn't able to do things like the others, because I was different. When I started having these breathing problems it all emerged, and then it went away with the program." – AB (patient) "I can give an example of a patient that stopped going with her girlfriends play cards because she was ashamed of being breathlessness and using oxygen. Now she plays because she knows how to deal with it." – PS (HP)
<u>Negative outcomes</u>					
Increasing social embarrassment and frustration	3 (9%)	0 (0%)	0 (0%)	3 (30%)	"Maybe the only downfall of being in a group is that they can't manage their frustration, they don't want to admit in front of their peers that they can't do the same." – TP (HP)
Theme: knowing more, doing better					
<u>Positive outcomes</u>					

Learning about the disease, its management and support network	9 (27%)	3 (25%)	0 (0%)	6 (60%)	"A lot of people still lack health education and here we learn a few things that make us want to know more and search." – AB (patient) "They learn more about the disease, the symptoms and their management, they self-manage it better." – JS (HP)
Demystifying beliefs and reducing catastrophizing	5 (15%)	1 (8%)	0 (0%)	4 (40%)	"I freed myself from some stigmas. I was always worried about what was going to happen and what people would think of me." – AB (patient) "Some beliefs are prejudicial to patients and impair the results of the intervention. Sometimes, demystifying a belief is helping the patient in a great way. And sometimes people surrounding the patient have maladjusted beliefs that limit them. Involving the family is very important." – PA (HP)
Managing burden of disease and care	9 (27%)	1 (8%)	5 (45%)	4 (40%)	"I had to delegate some things that I used to do. Now she is the one going to the pharmacy and bank." – JC (patient) "When I go swimming, I am more relaxed now. Before, I had to bring my cell phone to the swimming pool and ask the teacher to call me if my phone rang. I used to go shopping in a rush, and now I feel that he's doing better and I am calmer." – MC (IC) "Family members have the situation more controlled. They shared that they could enable patients to do what they wanted because they were no longer afraid they had a crisis. They knew how to manage it by themselves." – FM (HP)
Theme: keeping the doctor away and avoiding expenses					
Positive outcomes					
Reducing the impact of comorbidities	9 (27%)	3 (25%)	0 (0%)	4 (40%)	"It was better than going to the gym because here you guide us through the exercises and I never had an issue with injuries. I used to go to the gym and I got an injury in my hip because no one told me how to do the exercises properly." – JS (patient) "As they start to being more closely followed by medical doctors, their comorbidities are more controlled" – PA (HP)
Reducing use of medication and oxygen	9 (27%)	3 (25%)	1 (9%)	5 (50%)	"Now I use the inhaler less frequently. I used to take that medication several times a day and now is rare the time I use it." – JV (patient) "He stopped using the inhalers so much. Before, he had to sit on the bed and do it and then he stopped, but now that he left the program he is doing it again." – FT (IC) "We noticed that they don't need as much oxygen debit for training." – PR (HP)

Avoiding exacerbations	14 (42%)	5 (42%)	3 (27%)	6 (60%)	"I used to have a lot of crisis. I am not sure if there is a cause-effect relation, but I have not had a crisis in a long time." – JC (patient) "One year ago, by this time of the year, she spent the winter sick and we couldn't do anything. This year I ask her to go out with me because I see that she is doing well." – AM (IC) "Another thing is their exacerbations which get better. The exacerbations start to be shorter, with less impact on their lives, less frequent, and more spaced." – TP (HP)
Maintaining good blood pressure, heart rate and peripheral oxygen	5 (15%)	2 (17%)	0 (0%)	3 (30%)	"I got a lot better. Lately I have noticed that when I am at rest I go up to 98 percent of oxygen." – JC (patient) "The oxygen saturation tends to stabilize." – PR (HP)
Maintaining a balanced nutrition	5 (15%)	1 (8%)	0 (0%)	4 (40%)	"I changed a lot in my diet, because it is not only a full plate that matters. It's not the quantity but the quality." – AB (patient) "Nutrition is fundamental in PR and we get different results depending on the patient. We have underweight and obese patients and we need to have different attitudes towards each one of them." – AC (HP)
Reducing healthcare utilization	3 (9%)	0 (0%)	0 (0%)	3 (30%)	"It ends up being a positive effect because they spend money on the program but save it on several other things such as medication and hospitalizations." – FM (HP)
<u>Negative outcomes</u>					
Increasing the impact of comorbidities	2 (6%)	0 (0%)	0 (0%)	2 (20%)	"It can have a negative effect, the fact that we are asking someone to do an exercise they can't do due to another condition, if the patient doesn't tell us what he/she has, or if we don't refer him to another appropriate professional." – AO (HP)
Increasing costs with PR	9 (27%)	5 (42%)	1 (9%)	3 (30%)	"The only problem of the program is that some people can afford it and others can't." – MS (patient) "It would be good if there weren't any costs, because nowadays with our small pensions it is difficult." – MC (IC) "People who have economic difficulties eventually give up." – CP (HP)
Having the program far from home	8 (24%)	2 (17%)	2 (18%)	4 (40%)	"The accumulation of expenses with transports is not affordable by everyone." – AS (patient) "I really don't like the fact that we have to drive here because I don't like to drive and it is a bit far away from our home." - MC (IC) "It's easier when the program is in the community, rather than the hospital. It is closer to their homes and instead of going to the gym they go there. It's a different assistance." – FM (HP)

IC – Informal carers; HP – Health professionals

3.3. Stage two: themes

Five themes explained the generated outcomes. Strong agreement between the two reviewers was found (kappa=0.81, and 95 percentage of agreement). Themes comprised several life dimensions with triangulated perspectives of the stakeholders.

Having a healthy mind in a healthy body

Participants felt patients regained a sense of normality, by restoring part of their physical capacity, which allowed them to engage in activities with their loved ones with less effort. Patients felt proud of their new skills to face day-to-day challenges, and of being more fit to perform functional tasks without the help of a third party. Overall, they had a generalised feeling of well-being, of whole body equilibrium, no longer feeling trapped in a sick body. These improvements had a positive impact on IC as they showed contentment by seeing patients' improvements in general health and how they became stronger. HP felt gratified as PR gave back patients function to perform daily living activities, becoming part of the society again and having a role in their family. Through the decrease in respiratory symptoms and restless nights, patients and IC felt there was a boost in stamina to do more tasks on a day-to-day basis.

Although most of the outcomes were seen as positive, patients and IC felt PR also caused pain and fatigue on the day after the physical exercise sessions, limiting their ability to help on domestic tasks and participate on family or group activities.

As PR gave patients tools not only to control symptoms, but also to become less afraid of the course of the disease, there was a symbiotic relationship between a healthier mind and a healthier body.

"Now I can take a shower by myself, and I can also put my shoes on." - JC (patient)

"Before, when we went walking together he had to stop and do something. Now he comes with me and walks without stopping. I think that now I get tired faster than him." – IA (informal carer)

"What I value most in pulmonary rehabilitation is the quality of life it gives to patients. They become more integrated in their families and in the society." – AC (health professional)

I can('t) do it

Through a healthier mind and a healthier body, patients improved their mood and motivation, enjoying the sessions and establishing connections with each other and staff personnel. Patients became happier about their lives, more talkative with other people and laughed more often. Participants felt PR brought them motivation to face life challenges, and to be more proactive within the community. Overall, PR resulted in a modulation in patients' perception of their capacity to achieve goals, as they became more confident of their own abilities. Indeed, by acknowledging their potential, patients freed themselves from self-stablished limitations and became more liveliness and hopeful of their future. Similarly, HP felt they coped better with the disease and its consequences, regaining hope about their health status and longevity.

"I started to realise that I could do things, some limitations were in my head."- JC (patient)

"…she started to feel more motivated, more opened, more available to face the challenges of her own life." – AB (informal carer)

"I think that they cope better because they see that they are not the only ones with the problem, and when they see a patient with oxygen and realize that that person travels, goes on a plane and does everything they like to do, the situation becomes less of a monster." – TP (health professional)

Feeling fulfilled

The previous theme had a relevant impact on patients' fulfilment, as the improvement in self-confidence encouraged them to find a new purpose and meaning in life. PR brought patients a sense of completeness, as they recovered freedom from their carers and were proud to return to their roles within the family. Patients stopped seeing themselves as "the patient" and more like the husband and the father of someone, recalling the person they used to be before the disease. Through a strong family support system and PR staff, patients found a new sense of self and belonging, developing new friendships and hobbies, such as volunteering. By feeling they were not the only ones with the disease, patients felt their embarrassment in social occasions decreased. Identically, HP felt patients' frustration decreased with their fulfilment with life and their ability to accomplish tasks again, leading to a sense of self-efficacy. Furthermore, HP's views were that patients' sexual life improved, as they learned how to control dyspnoea and fear of adverse events, which contributed to their fulfilment with life.

"I used to be ashamed, because I wasn't able to do things like the others, because I was different. When I started having these breathing problems it all emerged, and then it went away with the program." – AB (patient)

"While some people languish due to the disease, here it was not the case. Since she came here - she came out of her shell, she started volunteering, and wanting to do new things." – AB (informal carer)

"People that were very isolated come to the program and share rides, they start coming to our Christmas parties and see friends they made when they were in the program. Some things they don't tell us but we see." – AO (health professional)

Knowing more, doing better

Learning about the disease, management strategies and support network allowed patients to handle better their respiratory exacerbations and mental health issues. This theme was related with the theme “feeling fulfilled” as patients felt PR gave them new insights and a will to engage in support groups by feeling free from preconceived ideas. HP felt PR gave patients tools for an effective self-management and that demystifying negative beliefs, such as not leaving home to avoid sickness, helped patients in an “enormous way”. Moreover, IC shared that they became calmer, more relaxed, by knowing how to help patients in difficult situations, and that nothing bad would happen.

“A lot of people still lack health education and here we learn a few things that make us want to know more and search.” – AB (patient)

“When I go swimming, I am more relaxed now. Before, I had to bring my mobile phone to the swimming pool and ask the teacher to call me if my phone rang. I used to go shopping in a rush, and now I feel that he’s doing better and I am calmer.” – MC (informal carer)

“Some beliefs are prejudicial to patients and impair the results of the intervention. Sometimes, demystifying a belief is helping the patient in a great way. And sometimes people surrounding the patient have maladjusted beliefs that limit them. Involving the family is very important.” – PA (health professional)

Avoiding doctors and expenses

By learning how to better self-manage themselves and how to deal with their symptoms, patients started to have less emergency visits and medication-related costs. Patients and informal carers recognised general health improvements, with a decrease in the use of short-acting inhalers and oxygen debit, relating it to a better health prospect. These improvements were linked by patients and health professionals to a stronger immune system, due to the practice of exercise and a balanced nutrition. The acknowledgment by health professionals of the decrease in healthcare utilisation was seen a good indicator of maintaining their health related physical fitness and quality of life. Although health professionals felt the expenses with PR were balanced by the decrease in healthcare utilisation, patients and informal carers thought the expenses with fees and transports were not bearable for everyone, which frequently lead to dropping out of programs. Thus, participants felt that having the program close to their homes, in the community, was both more convenient and less scary than in hospitals.

“Now I use the inhaler less frequently. I used to take that medication several times a day and now is rare the time I use it.” – JV (patient)

“One year ago, by this time of the year, she spent the winter sick and we couldn’t do anything. This year I ask her to go out with me because I see that she is doing well.” – AM (informal carer)

"It ends up being a positive effect because they spend money on the program but save it on several other things such as medication and hospitalisations." – FM (health professional)

Figure 1 provides a thematic map with the connections between these different themes after undertaking pulmonary rehabilitation.

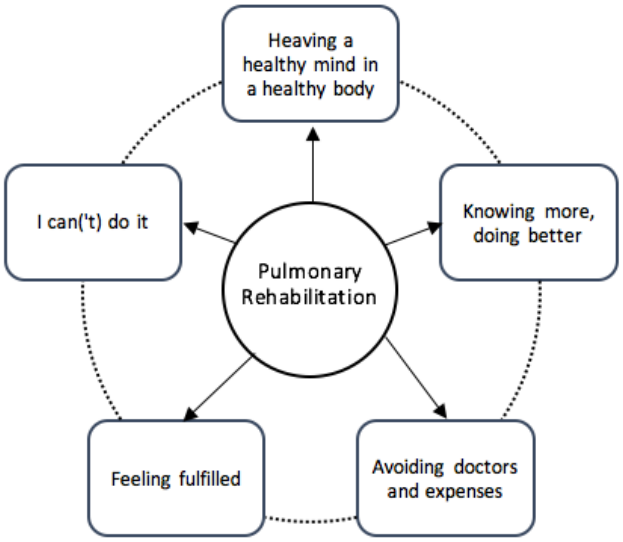

Figure 1 – Thematic map.

4. Discussion

This qualitative study constitutes one of the key phases for the development of a COS for PR in patients with stable COPD. To the authors' best knowledge, this was the first study investigating the valued outcomes of PR in the perspectives of patients, IC and HP, and the first to inform the future development of a COS for PR in COPD.

A list of 44 outcomes was developed which were organised under five themes, i.e., having a healthy mind in a healthy body; I can('t) do it; feeling fulfilled; knowing more, doing better; and avoiding doctors and expenses. These results can then be compared with the outcomes prevenient from a systematic review of the literature, and contribute for the development of a much-needed COS for PR in COPD. This study therefore, enhances our understanding of PR according to the perspectives of patients with COPD and their IC and not just according to the common perspectives of HP. Furthermore, it also informs the development of COS methodology, as although there are recommendations for qualitative studies to be included in a COS, most published COS do not have individual interviews, and those with qualitative research, usually include only one stakeholder group of the different ones involved in the intervention (39).

This study confirmed that COPD has a great negative impact on patients' lives, as the analysis of CAT scores revealed an impact above the normality (>10 points) (71), even

though all patients undertook PR. Although we had all grades of the disease represented in our sample, IC had mild burden of care according to the ZBI (≤40 points) (94). This is contradictory to what has been reported in the literature where IC of patients with COPD usually presented symptoms of distress, social isolation or professional problems (10, 122). It is therefore likely that PR had a positive impact on IC's burden, which is of most importance as they are commonly the patients' support system (123). The positive outcomes of PR on family coping have been demonstrated (124) and recommendations for including IC in PR have been given however, its effects on IC burden still requires further investigation (100).

Most reported outcomes of PR across stakeholder groups were "improving functional performance" and "reducing and taking control over dyspnoea". Whilst the improvement of dyspnoea in patients with COPD is well stablished as a positive outcome of PR (125), much less is known about the impact of PR on functionality and activities of daily living (126). The last Cochrane review on PR in COPD was unable to conduct meta-analysis with functional-related outcome measures (84). Even though some of the studies reported positive results for this outcome, its assessment was performed with a wide variety of measures. This is, indeed, a good example where the development of a COS could be useful to ascertain patients' response to PR in terms of their functional performance, as it translates to patients' quotidian and influences informal carers' burden (10, 28, 122).

Improvement in other symptoms such as fatigue, stamina and anxiety were also valued by all stakeholders as a result of PR. Whilst anxiety is commonly assessed in PR (28), fatigue and stamina are usually overlooked. Delivering PR programmes that fail to address these symptoms, valued by all but especially by patients, can lead to a lack in motivation towards exercise as patients might associate PR with negative feelings. This is of most importance as it could jeopardise adherence to intervention. Moreover, though motivation towards exercise has been described in the literature (123), the changes which PR can bring in their motivation towards daily activities, and confidence to face challenges of the quotidian, is yet to be explored (127).

Least but not less important reported outcomes, among all stakeholders were "improving body awareness", "reducing pulmonary function decline", "keeping an active sexual life" and "improving bronchial hygiene and cough". Although pulmonary function and its behaviour, such as the poor change in FEV_1 with PR, is well discussed in the literature (128, 129), there are few studies about the effectiveness of PR in cough and sputum and the usefulness of the most used scales to assess these outcomes (130, 131). Moreover, body awareness and sexual life emerge as important novel outcomes that could potentially be missed on the next stages of the COS, without the perspectives of the different stakeholders.

This study also highlighted possible negative outcomes of PR, such as fatigue, pain, social embarrassment and frustration, and impact of comorbidities. Increase fatigue, pain, frustration after undertaking exercise sessions in PR programs have been modestly described in the literature (132-135). Although, these outcomes can potentially lead to other health problems and poor adherence to the intervention (25), they are not usually assessed in PR. Thus, negative outcomes should also be considered in a future COS, as their consistent reporting would also enable comparison between trials.

Lastly, financial and geographical constraints were the biggest concerns to all stakeholders and should be taken into account when implementing PR programs. These aspects have been previously identified as potential barriers to the implementation of PR (12) however, again they are rarely reported and comparisons across studies are difficult. Since they could lead to severe financial consequences and poor adherence to a fundamental, evidence-based and well established intervention to these patients and families, careful attention to these topics in future research is needed.

This study supports the fact that COPD affects multiple life dimensions, and that PR is a comprehensive intervention with multiple potential benefits, that go beyond physical outcomes. Indeed, although perspectives were mostly consensual among stakeholders, some outcomes were only valued by health professionals (i.e., pulmonary function), whilst others were only valued by patients and informal carers (i.e., quality of sleep). Therefore, comprehensive assessments should be taken into account when categorising the patient into responder or non-responder to treatment, as specific assessments alone could lead to poor estimation of the effects of PR, and to a misidentification of priority in its access in the future. Multiple areas of life should also be represented in a future Core Outcome Set of this area, through the use of a pre-established framework of outcome domains (e.g. ICF, OMERACT)(41).

4.1. Limitations and Future Research

Although highly informative, this study has some limitations. Since the identification of outcomes from the interview transcripts was conducted only by one researcher who previously knew the participants, some bias might have occurred. However, the interpretative nature of qualitative studies requires the establishment of a solid rapport between the researcher and participants, and the interviewer is more likely to interpret the expressions of interviewees, taking into account their body language and registered notes. Moreover, data saturation was reached in all stakeholders.

Another potential limitation of these study is the diversity of HP included. Since PR is a multidisciplinary team it is possible that including other professionals would generate new outcomes. However, we have included the most common HP involved in PR around the world.

Furthermore, this study gives new insights for future studies aiming at exploring the differential response of patients with COPD to PR. Although this was a qualitative study aiming to inform a COS, future studies could focus on outcomes reported by these stakeholders that are seldom present in the literature, and yet highly meaningful not only for patients, but also for their IC and HP. Additionally, negative outcomes should be investigated, as they impact patients and IC's lives, ensuring a better management of COPD by HP.

5. Conclusions

This study has shown the importance of adding different stakeholders' views in the PR design, assessment and implementation. It has also informed the development of future COS methodology, as it generated outcomes that would have been missed if only outcomes prevenient from HP or researchers' views, were considered.

A total of 44 outcomes retrieved from this study will be considered for the next stages of the development of a COS for PR in patients with stable COPD.

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Annex I

COMISSÃO DE ÉTICA

da **Unidade Investigação em Ciências da Saúde - Enfermagem** (UICISA: E)

da **Escola Superior de Enfermagem de Coimbra** (ESEnfC)

Parecer Nº P466-10/2017

Título do Projecto: Desenvolvimento de um Core Outcome Set (COS) para a Reabilitação Respiratória de pessoas com DPOC

Identificação do Proponente
Nome(s): Sara Palos Souto de Miranda
Filiação Institucional: Instituto de Biomedicine (iBiMED) e na Escola Superior de Saúde (ESSUA) da Universidade de Aveiro
Investigador Responsável/Orientador: Alda Sofia Pires de Dias Marques

Relator: Ana Margarida Coelho Abrantes

Parecer

A DPOC constitui atualmente um desafio de saúde pública nacional e internacional tendo em conta que mundialmente ocupa o quarto lugar no que diz respeito à mortalidade e o sétimo quando referidos os motivos que causam incapacidade. Desta forma a reabilitação respiratória é considerada como uma estratégia fundamental na gestão da DPOC. Assim, este projeto tem como objetivos "desenvolver um Core Outcome Set (COS) para a reabilitação respiratória de pessoas com DPOC, de forma a definir um conjunto de resultados e instrumentos de medida mínimos para a avaliação dos resultados dos programas de reabilitação respiratória nesta condição". O projeto realizar-se-á em quatro etapas sendo que este pedido se refere unicamente às etapas I e III que visam a recolha de dados em pessoas com DPOC, respetivas pessoas significativas e profissionais de saúde associados a programas de reabilitação respiratória de pessoas com DPOC. O estudo decorrerá nas instalações da Escola Superior de Saúde da Universidade de Aveiro ou no domicílio de doentes com DPOC no período entre 01/12/2017 e 01/12/2022. Os critérios de inclusão e exclusão encontram-se bem definidos assim como os instrumentos de colheita de dados. A garantia de confidencialidade em todas as etapas.

Atendendo ao formato da investigação apresentado, a proposta reúne condições para aprovação por parte desta Comissão de Ética, não dispensando a autorização da instituição onde decorrerá a investigação.

O relator: _____

Data: 18.12.2017 O Presidente da Comissão de Ética: _____

Appendix I

Folha de informação ao doente/cuidador

O Sr./Sra. está a ser convidado/a para participar no estudo de investigação clínica intitulado: "Desenvolvimento de um Core Outcome Set para a Reabilitação Respiratória de pessoas com DPOC". Mas, antes de decidir participar ou não, é importante que compreenda porque é que a investigação está a ser realizada e o que é que a mesma envolve. Por favor, leia a informação com atenção e discuta a sua participação com outros, se assim o entender. Se houver algo que não esteja claro para si ou necessitar de informação adicional, por favor pergunte aos investigadores (contactos no final deste documento). Use o tempo que precisar para decidir se deseja ou não participar.
Muito obrigado desde já por ler a informação.

Qual é o propósito do estudo?
Este estudo visa compreender o que é importante para as pessoas que vivem com Doença Pulmonar Obstrutiva Crónica (DPOC), que tenham participado em programas de reabilitação respiratória. Para isso, estamos a entrevistar pessoas com DPOC que tenham tido a experiência de participar num programa de reabilitação respiratória, bem como os seus familiares, amigos ou pessoas significativas, de forma a conhecermos as suas experiências.

Este estudo fará parte de um trabalho mais alargado que terá como objetivo obter o acordo sobre como melhor medir os efeitos de programas de reabilitação respiratória em pessoas com DPOC. Assim, este estudo ajudará os profissionais de saúde e investigadores a comparar diferentes programas de reabilitação respiratória e a descobrir quais os melhores métodos, dentro do âmbito da reabilitação respiratória, para avaliar e tratar pessoas com DPOC. Este estudo faz parte de uma Dissertação de Mestrado em Fisioterapia.

Porque é que fui escolhido?
Foi escolhido/a porque é uma pessoa com DPOC em fase estável ou cuidador/a de uma pessoa com esta doença, que tenha participado num programa de reabilitação respiratória. Queremos recolher opiniões sobre os programas, de diferentes pessoas, com diferentes géneros, idades, etc.

Tenho de participar?
A decisão de participar, ou não, é completamente sua. Se decidir participar vai-lhe ser pedido que assine um formulário de consentimento informado, mas, é totalmente livre de desistir a qualquer momento, sem que para tal tenha de dar qualquer justificação. A decisão de desistir ou de não participar, não afetará a qualidade dos serviços de saúde ou qualquer outro, que lhe são prestados agora ou no futuro.

O que me acontecerá caso decida participar?
Se decidir participar, após assinar e entregar aos investigadores o consentimento informado, será contactado para agendar uma visita com um horário conveniente para si. Inicialmente será feita uma pequena avaliação do seu estado de saúde geral. De seguida, será gravada uma entrevista que poderá demorar entre 45 a 90 minutos e, que poderá ser realizada em sua casa ou nas instalações do Lab3R na Universidade de Aveiro, de acordo com a sua preferência. Poderá fazer pausas sempre que necessitar e até mesmo parar a entrevista a qualquer momento.

Quais são os efeitos secundários, desvantagens e riscos se eu resolver participar?
Algumas pessoas podem sentir-se ansiosas ao responder a alguns questionários, questões ou ao serem gravadas. Os investigadores são profissionais de saúde, que trabalham com pessoas com DPOC e terão o cuidado de assegurar que se sente confortável. Tanto os questionários como a entrevista poderão ser parados a qualquer

momento e poderá estar acompanhado por um amigo, familiar ou pessoa significativa durante toda a visita.

Quais são os possíveis benefícios se eu resolver participar?
Poderá não ter nenhum benefício com este estudo. No entanto, estará a ajudar as pessoas com DPOC ao contribuir para o conhecimento das razões pelas quais a reabilitação respiratória é importante para pessoas que vivem com a DPOC. Algumas pessoas poderão ainda apreciar a partilha da sua experiência na participação de programas de reabilitação respiratória, ou o apoio que prestam a quem o faça.

A minha participação será confidencial?
Toda a informação recolhida no decurso do estudo será mantida estritamente confidencial e mantido o anonimato. Os dados recolhidos serão salvaguardados com um código e palavra-passe, para que ninguém o/a possa identificar. Apenas os investigadores do projeto terão acesso aos seus dados.

O que acontecerá aos resultados do estudo?
Os resultados do estudo serão analisados e incorporados em Dissertações de Mestrado e alguns serão publicados em Jornais Científicos. No entanto, em nenhum momento o Sr./Sra. será identificado/a. Se gostar de obter uma cópia de qualquer relatório ou publicação, por favor diga ao investigador com quem contactar.

Quem é que está a organizar e a financiar o estudo?
Este estudo decorre no Laboratório de Investigação e Reabilitação Respiratória (Lab3R) da Escola Superior de Saúde da Universidade de Aveiro.

Contactos para mais informações sobre o estudo
Alda Marques (Orientadora Responsável)
Escola Superior de Saúde da Universidade de Aveiro,
Telefone 234 372 462
e-*mail: amarques@ua.pt*

Sara Miranda (Orientanda)
Escola Superior de Saúde da Universidade de Aveiro,
Telefone 910 344 616
e-mail: sara.souto@ua.pt

Folha de informação ao profissional de saúde

O Dr./Dra. está a ser convidado/a para participar no estudo de investigação clínica intitulado: "Desenvolvimento de um Core Outcome Set para a Reabilitação Respiratória de pessoas com DPOC (Fase II: Estudo Qualitativo)". Mas, antes de decidir participar ou não, é importante que compreenda porque é que a investigação está a ser realizada e o que é que a mesma envolve. Por favor, leia a informação com atenção e discuta a sua participação com outros, se assim o entender. Se houver algo que não esteja claro para si ou necessitar de informação adicional, por favor pergunte aos investigadores (contactos no final deste documento). Use o tempo que precisar para decidir se deseja ou não participar.
Muito obrigado desde já por ler a informação.

Qual é o propósito do estudo?
Este estudo visa compreender o que é importante para as pessoas que vivem com Doença Pulmonar Obstrutiva Crónica (DPOC), que tenham participado em programas de reabilitação respiratória. Para isso, estamos a entrevistar pessoas com DPOC que tenham tido a experiência de participar num programa de reabilitação respiratória, bem como os seus familiares, amigos ou pessoas significativas e profissionais de saúde envolvidos nestes programas, de forma a conhecermos as suas experiências.

Este estudo fará parte de um trabalho mais alargado que terá como objetivo obter o acordo sobre como melhor medir os efeitos de programas de reabilitação respiratória em pessoas com DPOC. Assim, ajudaremos os profissionais de saúde e investigadores a comparar diferentes programas de reabilitação respiratória e a descobrir quais os melhores métodos, dentro do âmbito da reabilitação respiratória, para avaliar e tratar pessoas com DPOC. Este estudo faz parte de uma Dissertação de Mestrado em Fisioterapia – ramo respiratória.

Porque é que fui escolhido?
Foi escolhido/a porque desenhou, implementou ou apoiou na implementação de programas de reabilitação respiratória em que foram incluídas pessoas com DPOC.

Tenho de participar?
A decisão de participar, ou não, é completamente sua. Se decidir participar vai-lhe ser pedido que assine um consentimento informado, mas, é totalmente livre de desistir a qualquer momento, sem que para tal tenha de dar qualquer justificação.

O que me acontecerá caso decida participar?
Se decidir participar, após assinar e entregar aos investigadores o consentimento informado, será contactado para agendar um encontro de acordo com a sua conveniência. De seguida, será gravada uma entrevista que poderá demorar entre 45 a 90 minutos e, que poderá ser realizada no seu local de trabalho ou nas instalações do Lab3R na Universidade de Aveiro, de acordo com a sua preferência. Poderá fazer pausas sempre que necessitar e até mesmo parar a entrevista a qualquer momento.

Quais são os efeitos secundários, desvantagens e riscos se eu resolver participar?
Não estão previstos quaisquer efeitos secundários, desvantagens ou riscos significativos por participar neste estudo. No entanto, algumas pessoas podem sentir-se ansiosas ao responder a alguns questionários, questões ou ao serem gravadas. A fim de minimizar estes sentimentos poderá, caso considere melhor para si, realizar a entrevista acompanhado(a). Salvaguardamos também que todas as informações que nos ceder serão mantidas anónimas e totalmente confidenciais. Adicionalmente, tanto os questionários como a entrevista poderão ser interrompidos a qualquer momento.

Quais são os possíveis benefícios se eu resolver participar?

Poderá não ter nenhum benefício direto com este estudo. No entanto, estará a ajudar as pessoas com DPOC ao contribuir para o conhecimento das razões pelas quais a reabilitação respiratória é importante para pessoas que vivem com esta condição de saúde. Algumas pessoas poderão ainda apreciar a partilha da sua experiência na participação de programas de reabilitação respiratória, ou o apoio que prestam a quem o faça.

A minha participação será confidencial?
Toda a informação recolhida no decurso do estudo será mantida estritamente confidencial e mantido o anonimato. Os dados recolhidos serão salvaguardados com um código e palavra-passe, para que ninguém o/a possa identificar. Apenas os investigadores do projeto terão acesso aos seus dados.

O que acontecerá aos resultados do estudo?
Os resultados do estudo serão analisados e incorporados em Dissertações de Mestrado e alguns serão publicados em Jornais Científicos. No entanto, em nenhum momento o Sr./Sra. será identificado/a. Se gostar de obter uma cópia de qualquer relatório ou publicação, por favor diga ao investigador com quem contactar.

Quem é que está a organizar e a financiar o estudo?
Este estudo decorre no Laboratório de Investigação e Reabilitação Respiratória (Lab3R) da Escola Superior de Saúde da Universidade de Aveiro.

Contactos para mais informações sobre o estudo
Alda Marques (Orientadora Responsável)
Escola Superior de Saúde da Universidade de Aveiro,
Telefone 234 372 462
e-*mail: amarques@ua.pt*

Sara Miranda (Orientanda)
Escola Superior de Saúde da Universidade de Aveiro,
Telefone 910 344 616
e-mail: sara.souto@ua.pt

Appendix II

Termo de Consentimento Livre e Esclarecido

Título do Estudo: "Desenvolvimento de um Core Outcome Set para a Reabilitação Respiratória de pessoas com DPOC"

Nome do Investigador Principal: Prof. Doutora Alda Sofia Pires de Dias Marques
Nome do Orientando: Sara Palos Souto de Miranda

Por favor leia e assinale com uma cruz (X) os quadrados seguintes:

1. Eu confirmo que percebi a informação que me foi transmitida e tive a oportunidade de questionar e de me esclarecer. ☐
2. Eu percebo que a minha participação é voluntária e que sou livre de desistir, em qualquer altura, sem dar nenhuma explicação, sem que isso afete qualquer serviço de saúde ou qualquer outro que me é prestado. ☐
3. Eu concordo em realizar esta entrevista e autorizo que as minhas respostas sejam utilizadas para o propósito do estudo. ☐
4. Eu concordo com a gravação da entrevista. ☐
5. Eu compreendo que os dados recolhidos durante a investigação são confidenciais e que só os investigadores do projeto da Universidade de Aveiro têm acesso a eles. Portanto, dou autorização para que os mesmos tenham acesso a esses dados. ☐
6. Eu compreendo que os dados recolhidos durante o estudo podem ser utilizados para publicação em Revistas Científicas e usados noutras investigações, sem que haja qualquer quebra de confidencialidade. Portanto, dou autorização para a utilização dos dados para esses fins. ☐
7. Eu autorizo ser contactado no futuro por esta equipa de investigação para participar na fase seguinte do estudo que consistirá num inquérito. ☐
8. Eu concordo então em participar no estudo. ☐

Nome do participante	Data	Assinatura
Nome do Investigador(a)	Data	Assinatura

Appendix III

Tema: Perceção dos resultados experienciados nos programas de reabilitação respiratória

Para a pessoa com DPOC: esta entrevista é sobre a sua experiência na participação em programas de reabilitação respiratória, desde que foi diagnosticado com DPOC. Por favor tente concentrar-se apenas na sua experiência. Esta entrevista será gravada, mas todas as suas respostas permanecerão anónimas, mesmo que refira nomes durante a mesma, pois estes serão alterados ou codificados. Esta entrevista demorará entre 45 e 90 minutos. Pode interromper a mesma a qualquer momento.

Para o cuidador informal, familiar ou amigo: esta entrevista é sobre a sua experiência no apoio prestado ao seu amigo/familiar no decorrer da sua participação em programas de reabilitação respiratória, desde que foi diagnosticado com DPOC. Por favor tente concentrar-se apenas na experiência dos dois. Esta entrevista será gravada, mas todas as suas respostas permanecerão anónimas, mesmo que refira nomes durante a mesma, pois estes serão alterados ou codificados. Esta entrevista demorará entre 45 e 90 minutos. Pode interromper a mesma a qualquer momento.

Guião[1]:

1. Fale-me dos programas de reabilitação respiratória de que fez parte;
2. **Pode-me falar um pouco da sua experiência** em participar nesses programas? (questionar locais onde foram realizados: comunidade, hospitalar, domicílio);
3. Para além dos doentes, quem mais esteve envolvido nesses programas? (família, profissionais de saúde ou outros);
4. **Que fatores o/a motivaram** a participar/prestar apoio em programas de reabilitação respiratória?;
5. Que razões levaram a que desistisse dos programas de reabilitação respiratória? (caso não tenha desistido: que razões o/a levaram a continuar no programa?);
6. **Que efeitos experienciou ao participar?** (Pedir efeitos positivos e negativos da reabilitação respiratória; solicitar os efeitos experienciados para o paciente e cuidador) (para alcançar profundidade na entrevista: por favor explore mais, diga-me mais sobre, consegue dar-me um exemplo? o que quis dizer com, consegue lembrar-se de mais algum efeito? mais alguém notou algum efeito em si?);
7. **O que valoriza mais na reabilitação respiratória?**
8. Se pudesse modificar alguma coisa no programa, o que sugeria?

[1] Nota: em negrito e sublinhado os tópicos a priorizar em caso de gestão de tempo

Tema: Contribuições para o desenvolvimento de um Core Outcome Set (COS) para avaliar programas de RR em pessoas com DPOC

Esta entrevista é sobre a sua experiência em desenhar, implementar ou apoiar programas de reabilitação respiratória para pessoas com DPOC. Irá contribui para a de desenvolvimento de um Core Outcome Set (COS) para avaliar a efetividade dos programas de reabilitação respiratória em pessoas com DPOC. O COS é um acordo de um conjunto mínimo de resultados e medidas que devem ser utilizadas como gold standard (em ensaios clínicos e prática clínica) na reabilitação respiratória da DPOC. Por favor tente concentrar-se apenas na sua experiência. Esta entrevista será gravada, mas todas as suas respostas, mesmo que refira nomes, permanecerão anónimas. Esta entrevista demorará aproximadamente 60 minutos. Pode interromper a mesma a qualquer momento.

Guião[2]:

1. **Fale-me sobre a sua experiência de estar/ter estado envolvido em programas de reabilitação respiratória em pessoas com DPOC**; (se a pessoa não partilhar a sua experiência profissional questionar - Fale-me um pouco do seu papel profissional nesta(s) experiência(s)).

2. Onde foram realizados esses programas (*settings*: comunidade, hospitalar, domicílio)?

3. Para além dos doentes, que outras pessoas estiveram envolvidas nesses programas?

4. **Pode partilhar comigo quais foram os objetivos** da reabilitação respiratória (do trabalho que desenvolve);

5. **E quais foram os instrumentos de medida que utilizou para avaliar os resultados da intervenção?** Fale-me um pouco sobre a sua experiência de os usar.

6. **Quais os efeitos que experienciou com** a reabilitação respiratória? (Pedir efeitos positivos e negativos da reabilitação respiratória) (para alcançar profundidade na entrevista: por favor explore mais, diga-me mais sobre, consegue dar-me um exemplo? o que quis dizer com, consegue lembrar-se de mais algum efeito?);

7. Quais considera serem os **principais resultados** a avaliar da reabilitação respiratória nesta população?

[2] Nota: em negrito e sublinhado os tópicos a priorizar em caso de gestão de tempo

Appendix IV

Scientific outputs developed under this dissertation

Articles:

Miranda Sara, Marques Alda (2018) "Triangulated perspectives on outcomes of pulmonary rehabilitation of patients with COPD – a qualitative study to inform a Core Outcome Set", Clinical rehabilitation (submitted)

Abstracts in indexed conference proceedings:

Marques Alda, Miranda Sara (2018) "Outcomes of Pulmonary Rehabilitation valued by patients with COPD – patients' perspectives", npj Primary Care Respiratory Medicine, supplemental issue (accepted).

Miranda Sara, Marques Alda (2018) "Triangulated perspectives on outcomes used in pulmonary rehabilitation of patients with COPD", European Respiratory Journal (accepted)

Abstracts in national conferences:

Miranda Sara, Marques Alda (2018) "Triangulated perspectives on outcomes used in pulmonary rehabilitation of patients with COPD", IV Simpósio de Pós-Graduação of iBiMED

Oral communications:

Marques Alda, Miranda Sara "Outcomes of Pulmonary Rehabilitation valued by patients with COPD – patients' perspectives", 9th 1st Ibero-American Primary Care Respiratory Conference and 9th IPCRG World Conference, 31 May 2018, Porto, Portugal

Posters:

Miranda Sara, Marques Alda "Triangulated perspectives on outcomes used in pulmonary rehabilitation of patients with COPD", European Respiratory Society International Congress, 14-19 September 2018, Paris, France

Miranda Sara, Marques Alda "Triangulated perspectives on outcomes used in pulmonary rehabilitation of patients with COPD", IV Simpósio de Pós-Graduação of iBiMED, 2nd July 2018, Aveiro, Portugal

Distinctions:

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